

Our Reference North East and North Cumbria ICB\
FOI ICB 26–260

North East and North Cumbria ICB
Pemberton House
Colima Avenue
Sunderland Enterprise Park
Sunderland
SR5 3XB

Tel: 0191 535 4288
E-mail: nencicb.foi@nhs.net

By Email

8 September 2026

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received on 21 August 2026 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000. The ICB covers the areas of County Durham, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

Please find the information you requested on behalf of the ICB as follows.

Your Request

I am writing to you under the Freedom of Information Act on behalf of Myeloma UK to request the following information:

1. What is the population currently served by the Integrated Care Board (ICB)?
2. Are you aware of how many people have a diagnosis of MGUS (monoclonal gammopathy of undetermined significance) within the ICBs region, and if so, how many?
3. Is there a current protocol/regional guideline for how MGUS patients should be monitored and managed within the ICBs region/remit (outlining the role of primary care, secondary care and laboratory services)?
4. How are MGUS monitoring services currently funded and commissioned within the region?
5. Please outline the role of primary care, secondary care and the laboratory in relation to MGUS monitoring and management in the region (inclusive of risk stratification guidance).
6. If possible, please outline all MGUS monitoring models operating within the ICBs geographic remit by hospital trust (including the use of virtual clinics and digital technology).
7. How much is spent per head of the population on current MGUS monitoring services/models within the ICBs geographic remit?

The format of the information supplied back can be in the body of email text or attached documents as appropriate (i.e. word document /PDF /excel spreadsheet if applicable).

Our Response

1. The ICB's population is publicly available data published by NHS England and can be accessed at [Patients Registered at a GP Practice – NHS England Digital](#). Therefore, the ICB considers this element of your request exempt from disclosure by way of s.21 as the information is readily accessible by other means.

For questions 2 to 5 and question 7, we can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide all the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested for Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland and Tees Valley.

However, we have determined that the information is held by the secondary care acute hospital NHS foundation trusts (FTs) and GP practices within the North East and North Cumbria region.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI contacts for all foundation trusts.

NENC Acute Hospital FTs	Email/Online portal
County Durham and Darlington NHS FT	cdda-tr.cddftfoi@nhs.net
Gateshead Health NHS FT	ghnt.foi.enquiries@nhs.net
North Cumbria Integrated Care NHS FT	foirequest@cumbria.nhs.uk
North Tees and Hartlepool NHS FT	nth-tr.foi@nhs.net
Northumbria Healthcare NHS FT	foi@northumbria.nhs.uk
South Tees Hospitals NHS FT	stees.foi.admin@nhs.net
South Tyneside and Sunderland NHS FT	stsft@infreemation.co.uk
The Newcastle upon Tyne Hospitals NHS FT	https://www.newcastle-hospitals.nhs.uk/help/foi/

In addition, and for your reference, a list of primary care practices is available on the NHS Digital website: [GP and GP practice related data – NHS England Digital](#). The GP Practices full file name is **eppracur** and for your reference, NENC ICB's Organisation Data Service (ODS) code is **QMH**.

The ICB does hold some information for the Central ICB region – Durham, South Tyneside and Sunderland. This has been provided below.

2. Figures are as follows:
Approx 954 Durham
Approx 746 Sunderland
Approx 404 South Tyneside
3. There is currently a LES commissioned across South Tyneside and Sunderland GP practices; the service specification extract is:

*Monoclonal Gammopathy of Undetermined Significance (MGUS)
MGUS (the presence of a paraprotein in blood) is a pre-malignant condition, which may progress to Myeloma, or in very rare cases, lymphoma.*

The Northern Cancer Alliance SNSS pathway requires a paraprotein and serum free light chain (PP and SFLC) check and thus increasing numbers of patients are being tested.

Testing for presence of PP is increasingly being requested in primary and secondary care for a wide range of symptoms (part of anaemia work up, part of GP myeloma screen, nonspecific bone pain, weight loss, fatigue, itch).

In those detected to have a PP, the risk of progression to overt cancer is highest within the first year but is low overall. The median age of those with MGUS is 70 years, affecting 3.2% of those over 50, increasing to 8.9% of those over 85-year-olds.

The theoretical goal of follow-up in newly detected MGUS is to detect early progression into MM or LPM, with the expectation that major complications will be minimised and survival prolonged owing to the initiation of timely treatment.

There is a consensus that all patients with newly diagnosed MGUS should have appropriate blood tests, FBC, creatinine, serum calcium, paraprotein and serum FLC levels (if available) performed 6 months after diagnosis, with annual follow-up thereafter, although the interval can be longer for patients with low-risk MGUS. The rationale for this approach is based on the observation that the risk of MGUS transformation is highest during the first year after diagnosis.

Practices will be required to:

- Ensure all patients with diagnosed MGUS are coded with the following SNOMED code MGUS-Monoclonal gammopathy of uncertain significance. Concept ID: 277577000.*
- Patient Leaflet – ensure each patient is provided with a Myeloma Info sheet.*
- Set up an annual recall for patients.*
- Ensure template is used for monitoring of MGUS.*
- Provide a Phlebotomy appointment and take bloods in accordance with guidance.*
- GP appointment to discuss blood results+ History + Examination and identify if referral is needed.*
- Follow annual monitoring requirements as per guidance.*

A similar service is commissioned in Durham GP practices:

Surveillance of Monoclonal Gammopathy of unknown significance (MGUS). Following an advice and guidance referral, primary care will receive a plan to monitor the patient and advice on when to refer back to secondary care.

- 4. MGUS monitoring services are funded through the Local Enhanced Service basket in Sunderland and South Tyneside and funded through the LIAISE basket in Durham.*
- 5. Please refer to the service specification information provided in response to question 3.*
- 6. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. However, we have determined that the information is held by the acute hospital NHS foundation trusts (FTs) within the North East and North Cumbria region. Contacts for these trusts are noted above.*
- 7. MGUS is monitored through a basket of services which includes various other services. The ICB does not hold a breakdown per patient.*

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Information Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or www.ico.org.uk.

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**